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Living with Worry: The Experience of Mothers with Deaf Child

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Abstract

Background

Born of a child with hearing loss is a stressful and unexpected experience for the parents. Understanding the experience of the mothers of children with hearing loss is a crucial to provide an appropriate care for this group of mothers. This study aimed to understand the concerns of the mothers who have a child with congenitally hearing loss.

Materials and Methods

In this qualitative content analysis, 35 mothers with child hearing loss participated in the semi-structural and deep interviews through a purposeful sampling method. Data were analyzed by using qualitative content analysis provided by Graneheim et al.

Results

Concerns of mothers of children with hearing loss were categorized in three main themes: 'the concerns of nature of hearing loss', 'the social concerns' and 'concerns about future'. Remarkably, the participants live with fear of the possibility of another deaf child birth in the next pregnancy or next generations were the most important concern of mothers.

Conclusion

Mothers of deaf children are experiencing the varieties of concerns. To cope with these concerns, they need a special consideration by society and health professionals. Modification of the concerns can decrease the child-related stress and consequently encourage them to involve in child care.

Key Words: Deaf children, Experience, Mothers, Qualitative content analysis.

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1- INTRODUCTION

Hearing impairment is one of the congenitally disabilities at birth time, and 1-3 per 1,000 children are born with severe to profound hearing loss (1, 2). Regardless of the type of culture and society, this situation provides conditions for increased challenges and problems in the suffering family (3). The diagnosis of child's deafness is a serious problem and a critical incident for parents (4, 5) and is often associated with unpleasant and stressful experience such as bereavement and stigma (5, 6). Disbelief, guilt, anger and hopelessness are among feelings experienced by parents during this period (7, 8). Studies have shown that children with hearing loss produce stress, anxiety, confusion, shame, social exclusion, and reproach of parents as well as emotional and social problems of children (9-11).

In such a situation, although all members of the family and its function impair, mothers feel and take a greater responsibility of their deaf child and face more pressures and problems because of their traditional role of caring (12,13). This affects also their mental health and adjustment (14). Physical and psychological needs of these children and the time and energy needed to take care of them are unique challenges for mothers (15). Since the mother is the first person who communicates directly with the child and is informed of his/her deafness (4).

Evidence suggests that disabled child initiates a painful mental process in the mother and creates a role conflict so that they do not see themselves ready for motherhood and feel guilty due to giving birth a disabled child; which per se leads to failure in achieving the expected motherhood (8, 13). The complexity and non-curability of the disability and its associated communication problems also affect the family life. Mothers may experience a lot of stress and anxiety even years after identifying hearing loss of their children (16). In addition, the diagnosis of deafness can exacerbate the negative perception of mothers from themselves and even lead to their social isolation. Although mothers cope with their child's hearing loss, they concern more about the attitudes of entourage and community towards the child's hearing loss (17). Mothers of children with disabilities often suffer from the problems and challenges related to their children (18). Mothers' concerns of their children not only impair their ability in the field of child care, but also may transfer to children (19). Thus; paying attention to the needs of mothers has a great importance. Hearing loss may challenge mothers and mentally involve them (20). Recognition of stress and anxiety-causing factors in mothers are necessary in order to reduce parents' stress and problems. In addition, further investigation is needed to explore the challenges and concerns of mothers of deaf children for providing strategies leading to adaptation of these mothers (21, 22). With respect with the high prevalence of child hearing loss and lack of a qualitative study on the experiences of mothers of the children with hearing loss in Iran, there is a necessity for identification of the psychological concerns of mothers having deaf children; so, this study aimed to understand the experience of mothers with a deaf child.

2- MATERIALS AND METHODS

2-1. Study design and population

The study was performed through the naturalistic method of qualitative content analysis. The participants were mothers of children with hearing loss covered by the Welfare Organization of Ardabil Province.

2-2. Measuring tools: validity and reliability

In-depth, semi-structured interviews were the primary method of information collection. As necessary, field notes and

records of post-interview comments were also used. Time and place of the interview were determined with the agreement of the participants. Thirty five interviews were conducted with 35 participants using purposive sampling. Interviews length varied from 20 to 50 minutes. Rigor of the study was provided using the criteria recommended by Denzin and Lincoln (23). Reliability and confirm ability of the study were ensured through review and confirmation of the findings by the participants and approval of the results by the study colleagues and two external researchers, respectively. The main themes of the study were given to 4 participants and they confirmed that the findings were true regarding them. To confirm transferability, the details such as the method of coding and formation of categories from raw data were explained to observers and the external researchers in order to judge about transferability of the data in other areas. The participants were selected from different socio-economic classes and different levels of education.

2-3. Ethical considerations

The present study is part of a nursing doctorate dissertation in Tabriz University of Medical Sciences. The study was approved by the ethics committee of the university (ID number: 5/4/3845). Some ethical considerations of the present study based on the Declaration of Helsinki included obtaining informed consent, scheduled interviews with participants, observing the privacy of individuals, explaining the objectives and methodology, confidentiality of information, the right of participants to withdraw from the study at any time, and taking approval from the Welfare Organization of Ardebil Province, Iran.

2-4. Inclusion and exclusion criteria

All mothers had children with congenital hearing loss and they were physically and mentally stable. At least 6 months had elapsed from the time of diagnosis of child deafness. All were Muslim and the age range was 21-50 years (**Table.1**).

2-5. Data Analyses

Sampling process continued until data saturation. All interviews were digitally recorded, immediately handwritten word by word, and analyzed through Graneheim and Lundman content analysis (24). The following steps were taken in the analysis: 1. word by word transcription of interviews and repeated review of them in order to understand their meaning, 2. considering the entire interview and observation as the unit of analysis, 3. splitting interview transcripts into hidden semantic units, 4. abstracting semantic units and assigning codes to them, 5. incorporation of initial codes into subcategories and main categories based on similarities and differences, and 6. comparing the categories with each other and in-depth and precise thinking for extraction of the main category. The data were analyzed and managed using the qualitative data analysis software of MAXQDA (version 10.0).

Table.1: Demographic findings and characteristics of the participants

Characteristics of the participants	Number/Age
Number	n=35 mothers
Mean age (year)	29.8 $\pm$ 0.348 (minimum 21, maximum 50)
Education	7 illiterates (20%), 18 diplomas (51.43%), 10 bachelors (28.57%)
Employment	12 employees (34.29%), 23 housewives (65.71%)
Family history	9 had family history (%25.71), 26 not had family history (74.29%)
Child gender	16 boys (45.71%), 19 girls (54.29%)

3- RESULTS

Thirty five mothers of children with deafness participated in this study. The average age was 29.8 ± 0.348 years old. The **Table.1** shows more additional demographic information about the study sample. Based on data analysis, the experiences of the participants about their concerns regarding deaf children were classified in 3 main categories (**Table.2**).

3-1. Concerns about the nature of deafness

3-1-1. Concerns about physical activity of children

Much of the concerns of mothers were related to physical activity of children. A participant said: "I always worry that my child falls at school or at leisure in the park and be damaged. All of these concerns exist. Even it crosses my mind that if he goes to the pool he will not hear the voices of others, these concerns exist" (P 5). Child deafness has raised concerns regarding the nature of children's safety in their mothers. As an important sense, hearing and speech power help children to ensure their safety in everyday life. In the absence of this capability, deaf children are susceptible to safety-related problems. One of the participants said: "I always worry. Worry that he may hit many things in the street, because he cannot hear and talk. A car may horn and he cannot hear and an accident occurs" (P 8). Another participant said, "I always worry. Worry that a problem might happen to him and he cannot call, or get sick and he cannot tell us" (P 15).

3-1-2. Concerns about the financial burden of rehabilitation for children

Some participants said that the cost of rehabilitation and care of children within the family is out of their financial strength. They stated that they are incapable of handling the high costs of deaf children. A 23-year-old mother who was a housewife with BA complained that: "The medical expenses are very excessive such as purchasing hearing aid batteries, changing the cast. We change the batteries 2 times a week. Unfortunately, state institutions do not pay these costs. The rehabilitation costs are too high: (P 9). Residents of small towns are often facing with the problem of accessing to deafness rehabilitation facilities and must go to provincial capital to receive health care. Time and long distance to access speech and hearing education services were concerns and problems for many mothers. A 27-year-old mother stated in this regard: "We are all worried about him, because we don't have access to facilities! For example, we live in a city where even there is any speech therapist. We must visit provincial capital at least 3-4 times a week which increases the costs several times" (P 12).

3-1-3. Concerns about the consequences of cochlear implant

Another concern for mothers with deaf children is lack of awareness about cochlear implant. In this regard, a 33-year-old housewife mother with diploma stated: "A relative had a cochlear implant. The internal prosthesis now is disabled, and this increased my concerns. My new concern now is to be like that, because nobody told us that cochlear implant can work to the end" (P 11).

3-2. Concerns about social problems

Another concern mentioned by the participants was worries about public reactions to deaf children.

3-2-1. Concerns about inappropriate public reaction to deaf children

Concerns about the negative attitude of others were a common experience of many mothers. They felt from the moment of diagnosis that they are not able to have a

positive look to the future because hearing loss is associated with negative images in society. The second participants said in her interview: "I was worried that can he educate in a regular school? Can he advance himself and be far from stigma, because society has not a good look to children like my son?" (P 7).

Some mothers felt reproaches from others during early days of detection of their child hearing loss, or were concerned of possible reproaches from others. A mother said: "I'm more concerned about people's reproaches. I feel that someone may taunt me or may say that my child had a hearing impairment" (P 25).

Concern about others' compassion is another experience revealed by mothers of deaf children. In this regard, a participant said: "I feel it. My child is a disabled, society pities him, and I am very concerned about it" (P 21).

3-2-2. Concerns about institutional support

Mothers knew coverage of their children by the Welfare Organization as a social source of discredit, embarrassment, and even shame, and they were very concerned. Therefore, they strongly were trying to hide this aspect of their social identity. One of the participants said: "I'm very worried about that people know my child is covered by the Welfare. I do not like anyone to know, both for my reputation and my daughter. Finally, she has a coming. She will have a suitor; I don't like people say an anecdotal about my child or say go away you are a welfare client. This is worrying me so hard when somebody says such a talks" (P 19).

3-2-3. Concerns about the behavior of friends of deaf children

Another major concern for mothers of children with hearing loss was concerns about unusual and abnormal behavior of the child's peers. Half of the participants stated that they fear that their children be labeled and be ashamed in the community. They are always living in fear of negative reactions of others. A 26- year-old housewife mother with high school diploma said in this regard: "I'm concerned that when he grows up, he will figure out that he should hear with a phone. At school age, he will understand and may be too embarrassed from his friends. This bothers me. If the child was a girl, she could use hearing aids under her scarf, but my child is a boy and this concern is always with me" (P 4). Rejection due to his inability to communicate with others was another concern mentioned by the participants. One of them said: "I am worried that he cannot communicate with his peers and always be rejected; this always worries me" (P 7).

3-2-4. In-adequate social support

Another concern mentioned by the participants was inadequate social protection of the deaf child. A participant stated: "In a sense, the state discriminates between children with and without hearing loss. As they're deaf, the government should provide special considerations for them" (P 5). Another participant said: "There is no support for these guys in society" (P 11). The next participant said: "These children can difficultly find a job in our society. I'm worried about his future so I bought a flat to be a source of income for him in the future" (P 22).

3-3. Concerns about child future

An important part of the experiences of mothers with deaf children were concerns about their child's future. Most mothers worried about the future of their children. Subcategories of concerns about the future included concerns about studying in special school, concerns about deaf child marriage, concerns about child's

occupational future, and concerns about birth of another deaf child.

3-3-1. Concerns about studying in special school

Some mothers were concerned of not accepting their children in regular schools. In this regard, a housewife 26- year-old mother with BA stated: "I'm more worried about his school. I think that can he go in a regular school? Or maybe a special school.... If so, I really cannot stand" (P 6). Another participant, 29- year-old educated mother, said: "I worry now more about his school. That is the more I get closer to her school time, I worry more. Is he finally will go to regular school?" (P 5). Another mother said: "I know that he has hearing loss and will not be like a healthy child. I cannot change him, I just encourage myself, and I expect he goes to a regular school. I always worry about his future. Will he able to study in a regular school and continue his university education?" (P 2).

3-3-2. Concerns about deaf child marriage

Concerns related to disclosure during marriage and childbearing of the deaf child were of the themes that the participants expressed their feelings and remarks about. The participant 5 said: "I'm worried that this issue will be raised if a suitor comes for her? What would be their reaction for this case? The suitor may be ideal, but he will give up because of the child deafness. These concerns exist". Another participant said about her concerns: "I'm worried about her future. I think it will be a little hard for her to marry. Nobody will marry with my daughter. Nobody likes to get married with such families, and face problems after marriage" (P 9). Concern about childbearing of deaf child was another concern highly regarded by the participants. The participant number 4 said: "Some children with hearing loss have hard hearing or deaf dad or mom. I'm worried and afraid that God forbid, if Mohammad Amin gets married, his children suffer from the same problem, and his children become deaf. My main worry and concern is now that what will happen in the future?" (P 4). Another said: "I worry about my son after marriage; how will be his baby? It's likely that their child be deaf, or perhaps healthy due to genetic, because we have not in our family" (P 21). Another participant said: "I worry in every aspect for marriage of my child and his children. These are a series of concerns that do not go away. These are always overwhelming and I think these concerns and problems are not finish able" (P 15).

3-3-3. Concerns about child's occupational future

Mothers were worried about the future of their children and believed that they will not have opportunities suitable with their condition. In this regard, a participant said: "Deaf children are having difficulty in finding jobs in the community" (P 23). Another mother stated: "I'm afraid that in the future he cannot adapt himself with the environmental and living conditions and cannot find a suitable job" (P 9).

3-3-4. Concerns about birth of another deaf child

Some of the mothers of deaf children did not want to get pregnant again because of fear and concern about the possibility of another deaf child. In this regard, a housewife 32-year-old mother with a bachelor declared: "I'm afraid that if I bring another child, he would be alike, and so I do not want to be pregnant again" (P 7). A housewife mother with high school diploma (23- year- old) said of her concerns about getting pregnant again: "One of my concerns is that I lost my first kid. I have a lot of stress for my next pregnancy, I'm afraid that these effects repeat. I'm always searching the Internet

about high-risk pregnancies" (P 26). A housewife mother with high school diploma (24- year- old) stated in this regard: "Now I should tell, I do not care for children, my husband is so. When he sees a problem, he is thinking always to not add another problem to the future" (P 22).

Table-2: The main categories and subcategories of concerns of mothers with deaf children

Subcategories	Main categories	Common theme of categories
Concerns about physical activity of children.	Concerns about the nature of deafness	Living in the shadow of concerns
Concerns about the financial burden of rehabilitation for children.		
Concerns about the consequences of cochlear implant.		
Concerns about inappropriate public reaction.	Concerns about social problems	
Concerns about institutional support.		
Concerns about the behavior of friends of deaf children.		
Inadequate social support.		
Concerns about studying in special school.	Concerns about child future	
Concerns about deaf child marriage.		
Concerns about child's occupational future.		
Concerns about birth of another deaf child.		

4- DISCUSSION

This is the first report of a qualitative study about concerns of mothers of deaf children in Iran. The main category was 'Living in the shadow of concerns' which consisted of the categories of concerns about the nature of deafness, concerns about social problems, and concerns about child future. One of the concerns understood by mothers of deaf children is related to the nature of hearing loss. In a qualitative study of 21 parents of deaf children in Canada, Fitzpatrick et al. (2008) showed the concerns of parents about the nature of hearing loss (25). In another study, some mothers worried about the nature of deafness and access to follow-up after diagnosis (26). One of the concerns associated with the nature of deafness in the present study was their motor activities. In a study by Meinzen-Der et al. (2008) on 152 parents of deaf children, mothers also concerned about the safety of children and the possible misuse of others (27). Perhaps one of the reasons for their concern was damage and breaking of hearing aid or phone due to physical activity of the child. Experiences of mothers with deaf children show that they are concerned about the financial burden of child rehabilitation. Children deafness imposes heavy costs on families in Iran which provisions sometimes leads to concern and arising of certain problems in the family. According to this study, low income of some families does meet the high cost of services, audiovisual education of children, purchase of hearing aid, and hearing aid batteries needed by children. High costs of hearing rehabilitation result in parental concern and stress. Occupational, educational, and social future of children, long rehabilitation programs and problems in the community for these children raises parental concerns and affect marital

adjustment (17, 28). In some studies, the parents of severe hearing loss or deaf children reported financial stress for the costs of auditory training sessions, speech therapy, hearing aids, and other medical equipment (7, 29, 30). Inappropriate reactions of society and some family members regarding child's deafness was one of the mothers' concerns in this study. The participants stated that the public compassionate with children because of their deafness, and most of them are concerned about attitudes of the people and society towards child's hearing loss. Tolerating curious and compassionate looks of the people to deaf children worry their mothers; this is consistent with the results of Olecká and Ivanová and Jakson et al. (7, 31).

The findings showed that many mothers of children with hearing loss concern about stigmatization of their children. Sense of rejection of children by friends and peers and endangerment of the friendly relations of the child are another concerns cited by mothers. The study by Rout and Khanna (2012) in India showed that many mothers were concerned about labeling disability to their child by others (32). In another study; rejection of deaf children by other people was mentioned as another concern of mothers. Negative reactions of people to deaf children in society and lack of understanding and acceptance of the child sometimes result in severe concern of mothers and lead them to isolation from public and leaving some connections (33).

Based on the results of this study, social support from family for providing services to deaf children is not desirable. The data showed that despite comprehensive support and efforts of the government regarding rehabilitation of deaf children, there is a large gap between available and desirable facilities. The lack of easy access to cochlear implants, lack of deaf associations in different parts of country, and inadequate protection of insurance companies are some of the problems in the community support system. These mothers believe that comprehensive support of the state is the prerequisite for rehabilitation of these children. In this study, concern about the child's future was found as a major cause of maternal stress, which constantly occupies the mind of all mothers. Research in the field of stressors in parents of deaf children shows concern about the future of children and impairment of family functioning as the most important stress factors for this parent (34).

In a longitudinal study on 23 mothers with deaf children, Lederberg and Golbach (2002) showed that children's communication problems and worries about his future are the main concerns of these mothers (9). In a study by Rout and Khanna (2012), independence, employment, and future of the children were the second priority of the majority of mothers (31). In the study of Jackson et al. (2008), most mothers had experienced some degrees of concern about the affection of family by their deaf child in the future (31). A study has shown that women are more concerned about this thought that who will take care of their disabled child after their death (35). Mothers (especially in the early detection of their children deafness) are shocked due to concern about the future of children and lack of sufficient awareness of disability and fear of its complications.

These pressures result in more anger and concern (20). The experiences of participants indicated that one of the main concerns about the future of mothers with deaf children is concerns about children's education, because mothers have to spend more time with their deaf children (36). The results of Jamieson et al. (2011) on 38 parents of hard hearing and deaf Canadian children showed that the parents experience increasing concerns about various aspects of life with deaf children. Most of them were worried about their

child's educational situation and opportunities in later life (37). In the present study, some mothers worried about their deaf child marriage. In the studies conducted by Burton et al. and Kobayashi et al., it was also shown that some of the mothers of deaf children were concerned about their marriage and the possibility of hearing loss of their children (38, 39). Moreover, fear of getting pregnant again and the possibility of birth of a deaf baby was one of the major concerns reflected in talks of these mothers. They looked to the next pregnancy as a risk factor, rather than a normal event of life. This finding is consistent with results of Nasiri and colleagues (21). In a study by Burton et al., mothers were concerned about hearing loss of their second child and children's of their deaf child (38). In another study, parents whose first child had a birth defect were concerned about getting pregnant again (40). The participants in the present study were very concerned about lack of equal opportunities in the future for their deaf children. These children should be independent in the future and able to manage their financial issues. This finding is consistent with the study of Raeis et al. Mothers are more concerned about the occupational and educational future of their deaf child than other family members (41).

4-1. Limitations of the study

The present study only reflects concerns of mothers of children with congenital hearing loss who were referred to the centers of Welfare Organization. Therefore, these findings may not be helpful regarding the mothers of children with acquired hearing loss, although one of the characteristics of qualitative studies is impossibility to generalize their findings.

5- CONCLUSION

Overall, the findings showed that one of the serious challenges of mothers with deaf children is living in the shadow of the concerns. These mothers experience different concerns including the nature of deafness, social problems, and the future life of children. Concern about the possibility of another deaf child, anxiety about marriage of the deaf child, and fear of deafness of the deaf child children were the main concerns of these mothers. These concerns affect all aspects of the life of this group of mothers and may damage their quality of life and impair their ability to support and rehabilitate their children. Therefore, due to the multiple concerns of mothers of children with hearing loss, it is necessary to pay attention to emotional, sentimental, and psychological aspects of these mothers in usual rehabilitation programs and services for children.

6- CONFLICT OF INTEREST

The authors declare no conflict of interest in this study.

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